Summative Evaluation of the Choice and Opportunity Project Strategic Initiatives Program

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Summative Evaluation of the Choice and Opportunity Project Strategic Initiatives Program

Final Report — Phase I

1995-1998

Evaluation and Data Development
Strategic Policy
Human Resources Development Canada
and
Government of Prince Edward Island
Canadian Association for Community Living
Prince Edward Island Association for Community Living

September 1998

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Acknowledgements

The Choice and Opportunity Project is a jointly funded federal-provincial Strategic Initiative which involves four partners — the governments of Prince Edward Island and Canada and the Canadian and Prince Edward Island Associations for Community Living.

This evaluation study was conducted by Goss Gilroy Inc. and the Institute for Human Resource Development, both of Newfoundland, under the direction of the Evaluation Committee comprised of representatives of the four partners.

The evaluation team would like to thank all those who contributed to the study, including families, individuals, caregivers and officials in East Prince who participated in the case studies, officials in the PEI

Department of Health and Social Services, members of the Steering Committee, the firm of Goss Gilroy Inc. and the Institute for Human Resource Development of Newfoundland.

Executive Summary

The Choice and Opportunity Project was announced in the Federal Budget of February 1994 as an example of the type of initiatives that would be supported under the new Strategic Initiatives Program.

The specific objectives for the Choice and Opportunity Project were described in the Framework Document approved by the four partners dated September 26, 1994:

> *"Choice and Opportunity is a joint project of two levels of government aimed at developing a new way of supporting the participation of individuals with an intellectual disability. The project will attempt to redesign existing programs and delivery mechanisms while at the same time providing more opportunity for individuals who have a mental handicap to make decisions about how they want to receive supports and services, and assisting generic agencies and community organisations to be inclusive of persons with a disability."*

The framework document identified the following rationale for such a radical restructuring of the existing situation:

> *"While there have been many recent improvements to their lives, persons who have a mental handicap ... face a variety of barriers to full participation as members of their communities. While millions of dollars are being spent ... the persons who are receiving existing supports and services are frustrated.... They feel they do not have enough say.... Too often, they are denied the opportunity to work; they cannot choose where they are going to live or with whom; they do not have access to education and training to prepare them for the job market; they lack opportunities to be involved in the social and cultural activities of their communities."*

Project Overview

The Choice and Opportunity Project is most easily understood as consisting of three components:

- **Model Development.** This component consisted of the

development of an alternative model for delivery of services to individuals with intellectual disabilities.

- **Community Development.** This component relates largely to efforts to develop community resources to support the approaches which comprise the model. Also included in community development are social marketing, policy formulation, communication with key stakeholders, issues relating to sustainability and preparation for province-wide implementation of the model.

- **Model Demonstration.** A key component of the project was the demonstration of the model on Prince Edward Island. The demonstration was undertaken in the East Prince Health Region. The goal of the model demonstration was to identify lessons learned to ease future implementation of approaches advocated by the model both on Prince Edward Island and in other provinces.

The Choice and Opportunity Project was implemented via a partnership of the Government of Canada (represented by Human Resources Development Canada); the Government of Prince Edward Island; the Canadian Association for Community Living (CACL); and, the Prince Edward Island Association for Community Living (PEIACL). As noted in the formative evaluation, a strength of the partnership model — and the specific partnership — was that it brought scope and diversity of thought to the very challenging undertaking which the project represented.

The evaluation has examined and reported on the three project components separately. While a previous evaluation was conducted, it was unable to fully address all the formative issues since the project itself remained in a formative or developmental stage until well after the formative evaluation was continued. Consequently, the current evaluation examines in some detail issues of relevance, design and delivery as well as issues related to project success. This focus — as well as the difficulties in communicating with members of the client population — has required the use of largely qualitative methodology.

The methodologies applied to the evaluation are as follows:

- an extensive review of the documents produced throughout the project;

- key informant interviews with representatives of the four partners in the project as well as interviews with officials of East Prince Health Region who were responsible for the project demonstration;

- 15 case studies relating to individuals with intellectual disabilities in East Prince;
- a workshop with representatives of the provincial government and PEIACL from all five regions held in the fall of 1997;
- community case studies were conducted in two regions (Queens and West Prince) in June, 1998.

The evaluation has addressed a total of 45 issues. In the report, each question raised by these issues has been answered to the extent that the evidence collected allows. This Executive Summary reports on the major findings relative to each of the three project components and subsequently on the lessons learned which might be applied to future similar endeavours.

Model Development

The model development component was concerned with developing a new approach to service delivery to individuals with intellectual disabilities. The model development phase sought to take advantage of the knowledge and expertise of CACL and the Roeher Institute. Consequently, these organisations had significant responsibilities in this component.

At the same time, the partners sought to ensure that the model would be responsive to local needs and conditions. Consequently much of the research conducted in the first two years of the project served a joint purpose of guiding the model development and guiding the community development initiatives.

To further ensure that the model would be responsive to local needs and conditions, a Model Development Working Group was struck. This group was chaired by the Province's representative on the Operations Committee. The Roeher Institute provided technical expertise and knowledge to the group and also facilitated some of the group discussions. Parents and service providers from each of the five health regions in the province were represented in the group.

Representatives of all four partners were actively involved in discussions and decisions relating to the model which was ultimately agreed to.

Development of the model proved to be a time-consuming process. The final report of the working group was produced on May 6, 1996 — more than two years after the announcement of the project. The model description produced at that time consisted of a conceptual framework for a new approach to service delivery.

While support for a move to the demand-based approach was universal, a number of operational constraints were identified by various individuals (see Issue 3). Most informants attributed this to a lack of operational focus within the model developed. In particular, informants described the model as "a conceptual framework, not a model", "motherhood", and "we don't have a model". A fundamental conclusion of this evaluation is that the model development process was not completed and that the "model" which was turned over to the East Prince Health Region was not implementable.

Our evidence indicates that the Choice and Opportunity Model was not a model but instead a vision. In effect, it painted a picture of a better approach but it did not describe how to get there. Our informants were in general agreement with this vision but quite critical of the amount of time it took to get there.

Community Development

One of the underlying assumptions of those who promote community living and the Choice and Opportunity Project is that there are resources within communities to respond to the needs of persons with intellectual disabilities. The thrust of the community development component is building the capacity of communities (key leaders, community service clubs, businesses, churches, recreational groups, municipal councils, education systems, etc.) to be able to integrate persons with intellectual disabilities as meaningful citizens.

Based on interviews, focus groups and a review of project documents, community development in the Choice and Opportunity Project has included:

- making contacts with businesses to educate them on the Choice and Opportunity Project and the potential contribution of persons with disabilities;
- involving parents in planning for service delivery strategies;
- finding creative supports for individuals to help themselves and articulate their needs;
- working with NGOs in finding new ways to move individuals into the community;
- helping families, particularly older parents of persons with disabilities, to deal with their fear of change in service delivery strategies;
- promoting community partnerships with business, families and

government workers;

- talking to a full range of community resource persons about Choice and Opportunity;
- working with staff in group homes to include parents in the planning process;
- identifying people in the community vital to the success of the project;
- involving community resource workers as part of community committee structures;
- understanding that any community development initiative needs to be guided by issues related to sustainability;
- recognising that the system needs to support the role of the family support worker as a legitimate partner in the community development process; and
- understanding that community development strategies are driven by family/individual needs.

Both in the community case studies and in the focus groups relating to community development, we identified several examples of how individuals, organisations and businesses have reached out and included individuals with intellectual disabilities. Of the two community case studies, progress seems to have been greatest in Queen's County, and Association for Community Living (ACL) representatives noted several instances where they have been approached by individuals and organisations wishing to include individuals with intellectual disabilities.

Assessing the extent to which community development has succeeded is difficult at this time. Information from the evaluation of the Social Marketing initiative will provide some insight as to changes that have occurred over the past three years. Our evidence consists of:

- evidence from key informants indicating positive responses from individuals/organisations who were asked to include an individual with an intellectual disability;
- evidence — at least in Queen's County — that some organisations/individuals were starting to take a proactive approach to inclusion;
- several examples of individuals whose lives include greater inclusion than in the past; but ...

- the reality is that most adult members of the population remain largely isolated — either at home or in segregated programs.

This continuing degree of isolation is not — in our judgement — evidence that community development has failed. Instead, it is attributable to a variety of other factors:

- **Health and other barriers of participants.** Several of the individuals in our case studies have not become more involved in their communities because of poor health or other disabilities. These difficulties are not insurmountable but greater inclusion of these individuals will require more than acceptance by the community.

- **Lack of change by service providers.** Most adult members of the population continue to be served by agencies or businesses which were formed to serve this population. The evaluation has not included a comprehensive review of all service providers. However, our evidence indicates that change in the service providers has been minimal and that their services -— for the most part — are provided in isolated environments.

- **Lack of progress in implementing a resource allocation model.** The Choice and Opportunity Project has not lead to any significant change in the mechanisms whereby supports are provided to individuals. In the demonstration region, some individuals received access to incremental supports during the demonstration. However, no significant progress was achieved in reallocating funding from service providers to individuals.

Continuing benefits can be expected to be achieved from further community development efforts. However, as has been understood from the outset by the project partners, for those benefits to be sustainable it is necessary to help individuals take advantage of their more inclusive communities by reallocating funding from agencies to individuals.

Through the evolution of the project, PEIACL was primarily responsible for community development. PEIACL was a logical choice to implement the community development component, since this would not be consistent with the government's role, i.e., for policy development and program implementation. However, as noted in Issue 5 of Chapter 3, the specific mechanism for funding PEIACL's involvement has limited their accountability for specific achievements to the other partners. In practice this has meant that PEIACL — rather than the partnership as a whole — has been responsible for community development. This has limited the achievements under community development.

First of all, it has limited the contributions from CACL and HRDC. CACL and HRDC, with their national mandates, have knowledge of community development experiences in other jurisdictions and with other client groups. As well, both organisations have resources of potential value. Clearly, PEIACL consulted and made use of this knowledge and resources. Nevertheless, a greater involvement by CACL and HRDC in the design and monitoring of the community development process would have been valuable.

The limited role of the Government of Prince Edward Island in community development was a more serious limitation. The provincial government had two important roles to play:

- to assist in the definition of the scope of community development efforts. Their particular contribution would have been in identifying priorities based on where the formal system could best take advantage of community resources; and

- with a greater involvement in defining and prioritising needs, the province would have had a greater responsibility to make use of community resources and to work in concert at an operational level with PEIACL and others. The overriding responsibility of PEIACL for community development had the unintended effect of limiting the province's accountability for making greater use of community resources.

The partnerships at the operational levels have thus had different levels of success. For the most part, the community resource workers and the family support workers share the project's philosophy and principles. The partnerships become unclear in regions that have not identified a formal mechanism for partners to work together on specific objectives and implementation plans. Some key informants expressed confusion as to the lack of clear roles and mechanisms that link the partners. Based on our focus groups, the working relationship among the various stakeholders appears stronger in some regions than others.

Model Demonstration

One of the goals of the Choice and Opportunity Project was to demonstrate the resource allocation model and to learn lessons which would assist in possible future implementation of the model in other jurisdictions. The East Prince Health Region was selected for the model demonstration. The demonstration commenced in December 1996 and continued until March 1998. The East Prince Health Region is a largely rural area of the province which includes the community of Summerside.

For the majority of individuals with intellectual disabilities in the demonstration region, the Choice and Opportunity demonstration made little difference. There are two primary exceptions:

- **Pre-schoolers.** The Choice and Opportunity Project implemented an early intervention project for pre-school children with autism-like symptoms. A consultant was hired to work with seven families in East Prince and the project also funded participation of the families in a recognised intervention program (CARD), on a proposal put forth by a local paediatrician. This early intervention approach is consistent with the literature and can be expected to greatly enhance the potential for these individuals to be productive members of their communities.

- **Individuals who were clearly dissatisfied with pre-existing services.** The demonstration staff concentrated their efforts on individuals and families who were clearly dissatisfied and had complained about the services they received. Many of these were either using conventional services (i.e., Community Connections) on a limited basis or not at all. Several of them were individuals who had specific well-defined needs which could not be met within the funding system that existed prior to the project (e.g., speech therapy, access to greater amounts of respite care than allowed under the province's guidelines).

This focus on specific populations was a significant diversion from the intent of the model; i.e., to implement a new and more inclusive approach to providing services for all members of the population. It was also quite logical given that — as previously noted — the demonstration staff had received no guidance as to how to apply the model with individuals who were significant consumers of the services provided by Community Connections.

From the case studies, it is clear that dissatisfaction with the Choice and Opportunity Project was very high among the families of persons with intellectual disabilities. The common perspective was that the Choice and Opportunity Project was an expensive program that has not resulted in sustaining services to persons with disabilities in East Prince. For adult persons with intellectual disabilities, family members noted that the project enhanced neither choices nor opportunities. There was a consistent message from families, some of whom have participated in numerous forums, programs and reviews over the past 30 years, that the need is for action not deliberation and research.

A particular concern related to services for adults. Before, during and after the demonstration, Community Connections remains the one stable organisation offering services to this population. Families and

individuals were not universally pleased with this service and were dismayed with the lack of alternatives. In addition, some were very concerned that (in their view) the Choice and Opportunity Project was attempting to destroy a service that they knew and relied on without any viable alternatives.

A partial exception to the general view of dissatisfaction relates to the families of the pre-schoolers. These families were delighted with the intervention worker who assisted them and clearly identified substantial benefits that had been realised by their children as well as substantial strengthening of their families. They were very grateful that the Choice and Opportunity Project had made these benefits possible. However, there was also some resentment that they had lived with the threat of cancellation of this initiative. They were dumbfounded by the decision to withdraw Choice and Opportunity funding in June 1998 in view of the enormous benefits which had been realised by their families.

Lessons Learned

The Choice and Opportunity Project has sought to make important and difficult changes to existing approaches for providing services for individuals with intellectual disabilities and their families. The project has fallen short of expectations but many important lessons have been learned.

Need for comprehensive planning and accountability

The first lesson relates to the need for comprehensive planning and accountability in order to accomplish reform of government social service systems. Government social service systems serve disadvantaged individuals. Consequently, it is critical that reform initiatives incorporate comprehensive planning and accountability to ensure that:

- the specific goals of the reform are identified, agreed to and pursued; and
- the pursuit of these goals does not put clients at risk during the transition.

This did not occur in the Choice and Opportunity Project and, inevitably, the scope of the reform was reduced.

Defining roles and responsibilities in a partnership

The second lesson relates to the importance of defining roles and responsibilities in a partnership. It is difficult to conceive of a more challenging partnership than that created for the Choice and

Opportunity Project. Partnering between the federal government, a provincial government and a national and a provincial advocacy group was bound to be difficult. Doing so on a groundbreaking project whose scope was so complex and comprehensive (but somewhat unclear) increased the inherent difficulty. As noted in the formative evaluation, the Choice and Opportunity Project required such a partnership. Those who advocate community living had long sought the kind of changes which the Choice and Opportunity Project was designed to develop and test. On their own, they could advocate for change to government systems as well as assist individuals and their families. However, in partnership with government there was also the opportunity to reform the systems and processes of government. The failure to define clear roles and responsibilities — including accountabilities — for each of the partners became a limiting factor. There was no clear allocation of responsibilities as would be expected in a co-operative approach among equal partners pursuing the same agenda.

Reform requires the strong commitment of the owner

The Choice and Opportunity Project sought the reform of the provincial government's approaches, policies and systems for delivery of services to individuals with intellectual disabilities. However, the "owner's" commitment to the reform process was somewhat ambiguous throughout the project and its limited achievements. The project was consistent with the Government of Prince Edward Island's health reform strategy and this was perceived as a major advantage. But implementation of health reform was a major undertaking in itself and the Choice and Opportunity Project while consistent with health reform was a significant complication which became a lower priority. As well, a subsequent change of government resulted in reassessment of health reform and this lead to confusion regarding the Choice and Opportunity Project. Finally, the lack of a clear operational focus (see below) on the project made it very difficult for the provincial bureaucracy to commit to the project.

An operational focus is required in order to test new approaches

A model or concept cannot be implemented without adequate instructions on what the operational elements are; what activities should be carried out and in what sequence; what the criteria are for qualifying for supports; who will provide the services and what indicators are to be used to gauge client satisfaction and effectiveness. The lack of a clear plan as to how to implement the model resulted in a much less comprehensive demonstration than had been anticipated. The Choice and Opportunity Project did not hold the model development team accountable for providing an operational model. What was provided to East Prince was a vision of a resource allocation system without adequate instructions on how to implement

it.

In relation to disadvantaged populations, the public has a low tolerance level for research without action

The Choice and Opportunity Project was directed at individuals with a significant disability. Most of these individuals are dependent on the state and/or their families, and many lead difficult lives. Research into their difficulties and needs creates expectations for better service. Failure to meet these expectations will inevitably lead to dissatisfaction. This was apparent in interviews with families who had participated in numerous forums, programs and reviews over many years. They wanted action, not deliberation and research.

Transition strategies are essential for radical change

When instituting radical change, there is a need for a comprehensive transition strategy with milestone dates and expected results. It is difficult to move from the service approach that has been in place for many years to a more responsive and inclusive approach. Individuals need assurances that they will not have a lower level of service and that they will have an opportunity to test the new service before the old one disappears.

Sustainability will only be achieved when the system and the communities are able to reallocate resources according to the principles outlined in the model

Community development can achieve continuing benefits but individuals must be assisted in taking advantage of the more inclusive communities through a reallocation of funding from agencies to individuals.

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Management Response

The purpose of this letter is to respond to the Summative Evaluation of the Choice and Opportunity Project: Final Report — Phase I, 1995-1998. We request that this letter be incorporated into this evaluation document.

The evaluation report provided a comprehensive and fair reflection of the activities involved in Phase I of the Choice and Opportunity Project. The authors of the report have done an excellent job of describing components of the project and have summarised the learning of Phase I accurately. As representatives of the four partners

involved in the Choice and Opportunity Project, the Steering Committee does feel some of the concerns were overstated and somewhat incomplete in that the broader context was not fully included in the discussion. Without full consideration of these contextual issues and an awareness of Phase I of the Choice and Opportunity Project, a clear understanding of the project and its relative contributions is not truly possible.

We believe the evaluation report did not appropriately address or describe the context in which Phase I was launched and implemented. The Choice and Opportunity Project, as part of the Federal Strategic Initiatives Program, was from the outset a complex and unusual partnership. The project involved two levels of government, federal and provincial, and two levels of associations representing persons with intellectual disabilities and their families, PEIACL and CACL. Although the formal agreement was signed by only the two levels of government, there was throughout the project a four-way partnership. This partnership worked towards providing increased opportunity for persons with intellectual disabilities to make decisions about how they received support and services; towards assisting communities to be more inclusive of persons with intellectual disabilities; explored options toward the redesign of existing programs, services and the overall provincial policy framework.

A major contextual factor faced by the Choice and Opportunity Project was the termination of the Canada Assistance Plan in 1996 and the introduction of the Canada Health and Social Transfer (CHST). This major restructuring of the manner in which social programs are funded in Canada created many logistical and operational difficulties for the project. As well, the potential success of the Choice and Opportunity Project was affected by changes in leadership within the provincial government. As the project unfolded, there was also significant re-structuring of the health and social service delivery mechanisms within Prince Edward Island. Due to the changing provincial environment, there were frequent changes in the partnership representatives within the Steering Committee. These changes in personnel and representation resulted in unavoidable delays and fluctuations in the extent and type of commitment to the Choice and Opportunity Project at all levels. The fact that the partnership survived these major upheavals should, we believe, be viewed as a major success and a testament to the strength of the partnership and its collective commitment to the overall objectives of the project.

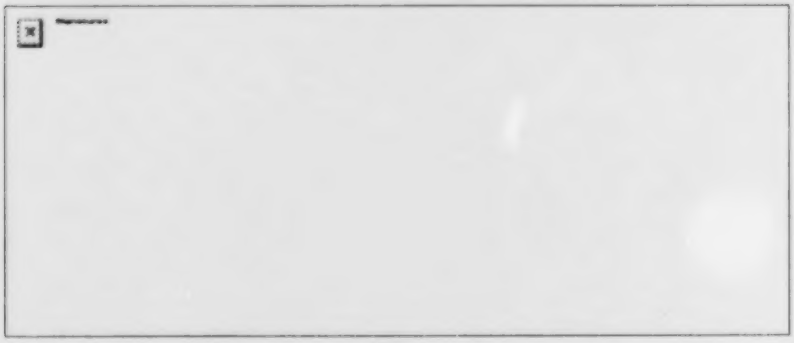
While it is acknowledged that Phase I of the Choice and Opportunity Project may not have met all initial expectations, the Steering Committee is confident the initial phase of the project did achieve success in many areas. In particular, the lessons learned within Phase I provide a foundation for further refinement and improvement to the service system and the broader policy framework. In fact, Phase I of

the Choice and Opportunity Project, the implementation phase, is designed to build on these lessons and will emphasise significant positive changes in the lives of persons with intellectual disabilities and their families. In particular, we believe there is much evidence to show individuals and families are now more involved in the planning process and that, overall, people with disabilities face fewer barriers to their full participation and inclusion in their community.

Phase I has witnessed a renewed commitment by all partners to achieving positive and tangible outcomes for persons with intellectual disabilities and their families.

There is no doubt the adoption of the philosophy and vision of the Choice and Opportunity Project has had a distinct and positive impact on the attitudes and behaviours of individuals at the grassroots level. It has already had a beneficial effect on the manner in which planning and service provision occur within this province. People with intellectual disabilities and their families are starting to take more control over the services and supports they receive. The service delivery system is starting to modify itself to conform to this change. While some of these changes are subtle, and have happened much slower than the Steering Committee would have liked, real change is occurring. It is our sincere belief and commitment that the Choice and Opportunity Project will, upon the completion of Phase I, have helped facilitate the continuation of this changeover and will ultimately serve as a model for other provinces and territories.

Respectfully,
The Choice and Opportunity Steering Committee



1.0 Introduction

This report describes the findings and lessons learned from the

Summative Evaluation of the Choice and Opportunity Project. The Choice and Opportunity Project was announced in February 1994 and Phase I of the project concluded in March 1998. The current evaluation — which commenced in November 1996 — represents the second evaluation conducted in Phase I. Summative evaluations are typically focussed on the impact, benefits and cost-effectiveness of the program or project evaluated. However, the Choice and Opportunity project was in many respects continuing to develop during the evaluation. Consequently, the evaluation has focussed on issues of relevance, design and delivery since the earlier formative evaluation did not fully address these issues.

The evaluation has also addressed issues relating to project success (in sections 3.3, 4.3 and 5.3). The client population — persons with intellectual disabilities — presents difficulties for use of the methods (i.e., surveys and quantitative measures) typically used to measure success. In particular, a large share of the clients are non-verbal and/or have limited ability to understand and communicate.

Therefore, the evaluation has relied primarily on qualitative methods. A further challenge was that a large share of the project resources was concentrated on the development of a new model for serving the client population. This activity clearly was intended to benefit the client population but was not directly focussed on client outcomes. An even larger share of the project resources was directed to community development. Community development was intended to change attitudes and practices in the community at large with respect to the inclusion of persons with intellectual disabilities.

The methodologies applied to the evaluation are as follows:

- an extensive review of the documents produced throughout the project;

- key informant interviews with representatives of the four partners in the project, as well as interviews with officials of East Prince Health Region who were responsible for the project demonstration;

- 15 case studies relating to individuals with intellectual disabilities in East Prince. These individuals and/or their families/caregivers were interviewed on three separate occasions — as the demonstration was starting (February 1997), approximately halfway through the demonstration (October 1997) and after the demonstration was completed (June 1998). With the permission of the individual and/or their family, interviews were also conducted with staff providing service to the person with the disability. These case studies were a key methodology for the findings reported in Chapter 5. Each case

was documented in detail. Since this information is highly confidential, the documented case studies are not generally available. However, a separate technical report, which summarises the results from the case studies, is available;

- a workshop with representatives of the provincial government and PEIACL from all five regions was held in the fall of 1997 to identify the nature, accomplishments and difficulties associated with community development efforts; and

- community case studies were conducted in two regions (Queens and West Prince) in June 1998 to identify the extent of change, which has occurred as a result of community development initiatives. A separate technical report is available which describes the results from these community case studies.

Analysis of administrative data was originally identified as a relevant methodology to measure the extent of change for persons on Prince Edward Island with an intellectual disability. Since the project has not actively targeted most of these individuals and since the changes which have occurred for individuals could not be measured from administrative sources, this has not been relevant.

The structure of this report is as follows:

- Chapter 2 provides a description of the project and the activities undertaken during the course of the project. Since the evaluation has examined three components of the project separately, these three components are defined in Chapter 2. Chapter 2 also includes a detailed accounting of the financial resources of the project;

- Chapter 3 provides the findings of the evaluation as regards the issues defined for model development;

- Chapter 4 provides the findings of the evaluation as regards the issues defined for community development; and

- Chapter 5 provides the findings of the evaluation as regards the issues defined for model demonstration.

Chapters 3, 4 and 5 are based on the issues provided by the Evaluation Committee. In total, these three chapters address 45 issues. The executive summary provides the major findings and lessons learned.

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2.0 The Choice and Opportunity Project

The Choice and Opportunity Project was announced in the Federal Budget of February 1994 as an example of the type of initiatives which would be supported under the new Strategic Initiatives Program. Strategic Initiatives was intended as a program which would support new, experimental initiatives jointly funded and implemented by provinces and the Government of Canada. The projects to be supported were new approaches that would provide learning as to possible alternative approaches to deliver social security programs to individuals in need. While the projects were implemented on a small scale in a single province with a well-defined target group, a requirement of Strategic Initiatives was that the pilot project have potential applicability to a wider population.

2.1 Rationale and Objectives for the Project

The specific objectives for the Choice and Opportunity Project were described in the Framework Document approved by the four partners dated September 26, 1994:

> *"Choice and Opportunity is a joint project of two levels of government aimed at developing a new way of supporting the participation of individuals with an intellectual disability. The project will attempt to redesign existing programs and delivery mechanisms while at the same time providing more opportunity for individuals who have a mental handicap to make decisions about how they want to receive supports and services, and assisting generic agencies and community organisations to be inclusive of persons with a disability."*

The framework document identified the following rationale for such a radical restructuring of the existing situation:

> *"While there have been many recent improvements to their lives, persons who have a mental handicap ... face a variety of barriers to full participation as members of their communities. While millions of dollars are being spent, ... the persons who are receiving existing supports and services are frustrated ... They feel they do not have enough say... Too often, they are denied the opportunity to work; they cannot choose where they are going to live or with whom; they do not have access to education and training to prepare them for the job market; they lack opportunities to be involved in the social and cultural activities of their communities."*

Clearly, this is a powerful rationale.

However, there are reasons why the existing flawed system has

continued to exist, not only on Prince Edward Island, but also in other Canadian communities. Indeed, the fact that delivery of services to individuals with intellectual disabilities is flawed across the country is a major reason that HRDC funded the project under the Strategic Initiatives Program and that the Canadian Association for Community Living participated as a partner in the project.

The existing services for members of the population tend to be delivered in relative isolation from the community at large. This is certainly an improvement from the time when members of the population were typically institutionalised. However, only for school-age members of the population is interaction with the community the norm. For pre-schoolers, service systems are generally not in place and these individuals are highly dependent on their families and the health care profession. The support received from the health care system is highly variable and the strains on families can be substantial.

Many adult members of the population are isolated from the general population. Increasingly, adults with intellectual disabilities are employed and/or contribute to their communities in other ways. Many others are isolated. In many communities, day programs exist where adults with intellectual disabilities attend. These programs have evolved somewhat from sheltered workshops, and often incorporate vocational training and community involvement as well as or instead of work. Nevertheless, the individuals who attend these programs often attend on a daily basis and for years at a time. These programs have been much criticised and clearly serve to isolate the population. However, the programs are typically full and have waiting lists. They may be flawed but they serve a very important role for persons with intellectual disabilities and their families or caregivers. At a minimum, they usually provide a safe environment for persons with intellectual disabilities. This allows families and caregivers to fulfil their other responsibilities and needs, which in turn makes ongoing family care for the individual feasible. Typically, they also provide opportunities for social interaction.

This dependence of individuals and their families on existing flawed systems does not reduce the relevance or rationale for reforming the system. It does make such reform much more difficult. The Choice and Opportunity Project was clearly an ambitious and difficult undertaking which set out to radically restructure the approach to providing services to persons with intellectual disabilities on Prince Edward Island.

2.2 Project Overview

The Choice and Opportunity Project is most easily understood as consisting of three components:

- **Model Development.** This component consisted of the development of an alternative model for delivery of services to persons with intellectual disabilities.

- **Community Development.** This component relates largely to efforts to develop community resources to support the approaches which comprise the model. Also included in community development are social marketing, policy formulation, communication with key stakeholders, issues relating to sustainability and preparation for province-wide implementation of the model.

- **Model Demonstration.** A key component of the project is the demonstration of the model on Prince Edward Island. The demonstration was undertaken in the East Prince Health Region. The goal of the model demonstration was to identify lessons to ease future implementation of approaches advocated by the model, both on Prince Edward Island and in other provinces.

The boundary between model development and community development is somewhat unclear. In particular, much of the research undertaken guided both the model development process and the various initiatives undertaken across the province.

The three components are each described in Sections 2.4 — 2.6. The financial resources of the project and how they were allocated to each of the three components are described in Section 2.7

2.3 Partnership

The Choice and Opportunity Project was implemented via a partnership of the Government of Canada (represented by Human Resources Development Canada); the Government of Prince Edward Island; the Canadian Association for Community Living (CACL); and the Prince Edward Island Association for Community Living (PEIACL). The roles of the partners were as follows:

- Human Resources Development Canada (HRDC) was the major funder of the project and provided $5 million in incremental funding over the four fiscal years starting in 1994/95 and terminating in 1997/98. HRDC participated fully in the design of the initiative and has been represented on all committees including the former Operations Committee, which guided the project during the first two years of operations;

- the Government of Prince Edward Island has not provided direct funding to the project. The Government of Prince Edward Island agreed to reallocate existing expenditures relating to

persons with intellectual disabilities to the extent successful implementation of the project required such reallocation. The Government of Prince Edward Island has responsibility for administration and operational implementation of the project. The Government of Prince Edward Island employed core project staff, although the related funding is provided by HRDC;

- CACL had a significant role in the design of the model for the project and has participated throughout, both through the various committees which direct the project and by providing technical support through the Roeher Institute. CACL brought to the project its expertise from past research into the approaches advocated by the model. As well, CACL brought its experience relating to the national context of social programs. CACL's involvement was financed directly by HRDC in years one and two of the project. Funding was provided at an equivalent level for years three and four from project funding;

- PEIACL has participated throughout the project and has been involved in all facets. The organisation has specific responsibility for the community development aspect of the project. As well, PEIACL has had a significant involvement in a variety of research conducted during the project. They are represented on all committees which direct the project. PEIACL's involvement has been financed from project funding.

2.4 Model Development

The model development component was concerned with developing a new approach to service delivery to persons with intellectual disabilities. The model development phase sought to take advantage of the knowledge and expertise of CACL and the Roeher Institute. Consequently, these organisations had significant responsibilities in this component.

At the same time, the partners sought to ensure the model would be responsive to local needs and conditions. Consequently, much of the research conducted in the first two years of the project served a joint purpose of guiding the model development and community development initiatives.

To further ensure the model would be responsive to local needs and conditions, a Model Development Working Group was struck. This group was chaired by the province's representative on the Operations Committee. The Roeher Institute provided technical expertise and knowledge to the group and also facilitated some of the group discussions. Parents and service providers from each of the five health regions in the province were represented in the group.

Representatives of all four partners were actively involved in discussions and decisions relating to the model which was ultimately agreed to.

Development of the model proved to be a time-consuming process. The final report of the working group was produced on May 6, 1996 — more than two years after the announcement of the project. The model description produced at that time consisted of a conceptual framework for a new approach to service delivery.

Consultants (Smith-Green) were then engaged to produce an operational framework for the model which would guide demonstration of the model. The consultants reported in October 1996 — about six months after the model description had been tabled. However, the consultants' report called for substantial changes to the structure and organisation of the project rather than providing the operational framework. At this point, the project was well behind its original schedule.

The Framework Document prepared in September 1994 stated:

> *"The project will attempt to redesign existing programs and delivery mechanisms while at the same time providing more opportunity for individuals who have a mental handicap to make decisions about how they want to receive supports and services, and assisting generic agencies and community organisations to be inclusive of persons with a disability."*

The developed model remained consistent with these principles and includes the following key elements:

- **Facilitators.** Skilled people, regionally based (who provide support to clients in the form of information, development of opportunities and alternatives, and support services), to assist with planning, to strengthen connections with the community and to provide help to gain access to funding.

- **Building a supportive community.** This consists of creating communities supportive to enabling social and economic inclusion of adults with intellectual disabilities and reducing reliance on formal programs.

- **Tools for fairness.** To ensure fair, efficient allocation of resources.

- **Tools for flexibility and innovation.** In financing, contracting and service review to promote responsiveness, portability, cost-effectiveness, and accountability.

- **Helping services.** Responsive to individual and family needs.
- **Resolving conflicts.** Methods and resources to prevent/address conflicts between family, individuals, community, service providers and funders.
- **Information.** Distribution of information required by individuals, families, service providers, funders and the public.
- **Improving the system.** Strategies and protocols to address ongoing concerns as the model is implemented.

This model represented a substantial deviation from pre-existing approaches on Prince Edward Island and in most Canadian jurisdictions. Traditionally, government has provided funding support to agencies which provide a range of services to persons with intellectual disabilities. Such funding has typically been provided in the form of service contracts. Under such arrangements, government's focus has been on the supply side. Government has influenced the nature of service provided both by what it paid for, and in monitoring the nature of services provided and the approach to service delivery.

The approaches espoused by the model change this focus from the supply side to the demand side or to meeting demands of persons with intellectual disabilities and their families.

2.5 Community Development

Community development was seen from the outset as the single most important factor to success of the project. This was due in part to lessons learned from de-institutionalisation efforts over the years. As well, it was recognised that a greater focus on demands and self-identified needs of clients would provide only very limited benefits if the choices available remained the same as prior to model implementation. Development of community resources was recognised as an essential activity that would avoid reinforcement of individuals applying for what exists rather than identifying what is needed.

Building capacities of individuals, families and communities was thus seen as essential for successful implementation of the model. It is noteworthy that community development was also a key component to the province's Health Reform Strategy and it was anticipated that initiatives and experiences from this broader reform would inform the project.

The project has addressed community development in a variety of ways:

- by strengthening the Prince Edward Island Association for Community Living. Before the project, PEIACL was a very small organisation. With project funding, the organisation hired staff who conducted research into the needs of the target population and attempted to develop the existing resources of communities to better the lives of persons with intellectual disabilities. This development initiative included public relations initiatives to increase the awareness of the general population, as well as working directly with persons with intellectual disabilities and their families and assisting them to take advantage of existing opportunities within their communities. By working directly with both persons with intellectual disabilities, their families, and community resources (e.g., employers, schools and community groups), PEIACL strives to both identify and increase opportunities for persons with intellectual disabilities to contribute to and participate in their communities in a meaningful way;

- by supporting other community organisations who seek to improve the lives of individuals with disabilities (People First, Citizen Advocacy). In particular, the funding support provided to these organisations was intended to remove barriers to their participation in the project and more specifically to engage them in addressing the matter of sustainability (see below); and

- by providing funding to each of the five Regional Health Authorities (RHA's) in 1995-96, 1996-97 and 1997-98. This funding was intended to engage the formal system in the regions in the project and also to prepare the other regions for future implementation of the model. In particular, the funding provided was intended to facilitate regional participation in the project so that regions could:
    - identify priorities in their region;
    - gather data on client demographics and current use of services;
    - reorganise in-house procedures or targeted services to conform more closely to the model;
    - network with the community and develop new partnerships; begin preparation for model implementation in each region.

Social Marketing

Social marketing has been conducted as a component of community development. Since it has been a significant initiative of the project, it is described separately. Social marketing is a tool that has been used by the project for the specific purpose of increasing inclusive behaviours of residents of Prince Edward Island. The project has

pursued this initiative with significant investment, resulting in a comprehensive plan which includes a variety of targeted strategies with clearly defined outcomes as well as an evaluation to determine the impact of social marketing on local attitudes. The plan was developed in October of 1996 as a product of the following activities:

- Carleton University conducted a Benchmark Study on the current attitudes and opinions of residents of Prince Edward Island regarding the integration of people with intellectual disabilities into the community;

- officials from the Government of Prince Edward Island and a number of organisations met for a two-and-a-half-day planning session. The session was facilitated by Carleton University. Input to the session consisted of:
  - the Benchmark Study data;
  - research conducted during the model development phase which identified the needs and concerns of persons with intellectual disabilities, their families and service providers on Prince Edward Island;
  - the variety of perspectives and experiences of the participants in the session.

The planning session resulted in a plan and schedule for a variety of communication and social marketing activities[1].

Other Initiatives

A variety of other matters have been addressed by the project and for evaluation purposes have been identified as community development:

- **Policy formulation.** The degree of change involved in the Choice and Opportunity Model was recognised as having policy implications for both the Government of Canada and the Government of Prince Edward Island. The project engaged consultant resources to prepare a policy framework and has engaged the partners and other key stakeholders in discussions relating to policy issues. The project also engaged consultants to address the legal implication of the Choice and Opportunity Model.

- **Communications.** The project has developed and implemented a strategy[2] to communicate about the project to key stakeholders. Project staff includes an individual who is responsible for implementation of the communications strategy.

- **Sustainability.** An explicit constraint for the model was the sunset nature of project funding. While incremental funding was available during the project, the full-scale implementation of the

model would have to be accomplished from pre-existing resources or, at least, with no additional funding from government sources. This has influenced all aspects of the project, ranging from the nature of the model developed, the approach to community development and the nature of supports available to individuals in the demonstration region.

- **Preparation for implementation.** All the partners have pursued the eventual implementation of the model throughout the province. Consequently, the project has dedicated resources to engaging key stakeholders in initiatives to prepare for implementation.

2.6 Model Demonstration

An important part of the Choice and Opportunity Project has been the demonstration of the new approaches advocated by the model. Delays in finalising the model development and budget reallocation have tended to limit the scope of the demonstration relative to what had been originally envisaged. The delays resulted largely from contextual issues including:

- reassignment of senior staff of the Government of Prince Edward Island;
- changes in the extent and nature of federal funding support relating to persons with disabilities (CAP, VRDP, CHST); and
- the parallel introduction of Prince Edward Island's Health Reform Strategy.

Further delaying and limiting the demonstration:

- the model produced by the Model Development Working Group remained at a conceptual stage and did not address the details of implementation in a way that would guide officials;
- the work of Smith-Green had been expected to produce an operational plan which would serve as a transition between the model development and model demonstration components. The report from that study recommended fundamental changes to the project and the roles of the various partners. We have no comment on the accuracy of these recommendations but note that they have not served to ease the demonstration of the model;
- the regional health authorities, who were expected to play a significant role in model demonstration, had very limited enthusiasm for the project;

- there was uncertainty about the status of the Health Reform Strategy and the future approach to delivery of health and social services as a result of a change of government in a recent election.

Ultimately, the East Prince Health Region was selected for the model demonstration. The demonstration commenced in December 1996 and continued until March 1998. Two individuals were initially employed full-time on the demonstration — a Demonstration Project Co-ordinator and a Facilitator. Senior officials from the Regional Health Authority and the Choice and Opportunity Project Director each played an important role in directing the model demonstration. PEIACL, and to a lesser extent, the other partners, participated in an advisory capacity.

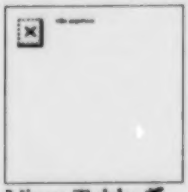
2.7 Expenditure Profile

The following expenditure profile is approximate in nature. The expenditures noted in the Amounts column are based on actual expenditures during the four years of the project[4]. The allocation of expenditures to the three components is approximate in nature and cannot be specified in a more rigorous fashion since the project was not managed as three separate components. However, the allocation of expenditures to components is based on our initial estimates, which have been modified based on feedback received from members of the Evaluation Committee. Since all partners are represented on the Evaluation Committee, the project totals for each component provide a reasonably accurate estimate of the size of the investment made in each of the three components.

The major purpose of the table is to illustrate the breakdown of total spending into each of the three components. As indicated:

- expenditures for model development are estimated at $1,048,000;
- expenditures for community development are estimated at $3,112,000; and
- expenditures for model demonstration are estimated at $840,000.

A variety of other relevant information is also evident from the table. In particular, project administration accounted for $1.4 million or 28% of total project expenditures.



View Table 5

3.0 Evaluation Findings — Model Development

The Evaluation Committee identified nine issues relating to the model development component:

- two relating to the relevance of the Choice and Opportunity Model;
- six relating to the design and delivery of the Choice and Opportunity Model; and
- one relating to the success of the Choice and Opportunity Model.

As indicated in the Issues/Indicators/Data Sources Table (see Methodology Report), the findings and evidence relating to these nine issues primarily evolve from key informant interviews and review of the documents prepared in the course of the Choice and Opportunity Project.

3.1 Relevance of the Choice and Opportunity Model

Issue 1 ***a) Is the resource allocation model suitable for the target group?***

We have found that the principles espoused by the model are universally accepted by the individuals interviewed in our work. All were concerned that the pre-existing approach to services does not adequately meet the needs of the population and serves to unnecessarily isolate persons with intellectual disabilities from their communities. The resource allocation model advocates a greater focus on the needs of the client population; self-selection of services to be accessed; and a greater use of support available within the community. By contrast, pre-existing approaches provide access to services which are specifically targeted to the population.

Table

Expenditure Item	Amount	Model Development	Community Development	Model Demonstration
***Expenditures Repeating each fiscal year*[5]**				
Grant to PEIACL	$300,000	10% in year 1 and 2; nil thereafter	90% each year	nil in year 1 and 2; 10% in years 3 and 4
Grant to CACL	$85,000	30%	35%	35%
Contracts/Grants - Roeher Institute	$35,000	100%		
Grants to other community organisations (People First, Citizen Advocacy)	$65,000		100%	
Project Staff, Administration and Equipment	$350,000	50% in year 1 and 2; 10% in year 3 and 4	50% each year	40% in year 3 and 4
Annual Total	$835,000			
Four-year Subtotal	**$3,340,000**	**$720,000**	**$2,160,000**	**$460,000**
Expenditures Repeating in 1995-96, 1996-97 and 1997-98				
Funding provided to East Prince Health	$140,000		25%	75%
Funding provided to four other Regional Health Authorities	$195,000		100%	
Annual Total	$335,000			
Three-year Subtotal	**$1,005,000**		**$690,000**	**$315,000**
Ad Hoc Studies and Consulting Contracts interspersed throughout the 4 years (allocated 50% to model development, 40% to community development and 10% to model demonstration)	**$655,000**	**$328,000**	**$262,000**	**$65,000**
Project Totals	**$5,000,000**	**$1,048,000**	**$3,112,000**	**$840,000**
Note: Of the $655,000 for Ad Hoc Studies and Consulting Contracts, $108,611 was spent on evaluation - $70,000 for the Summative Evaluation described herein and $38,611 for the Formative Evaluation conducted by WHM Group.				

While support for a move to the demand-based approach was universal, a number of operational constraints were identified by various individuals (see Issue 3). Most informants attributed this to a failure to complete the model development. In particular, informants described the model as "a conceptual framework not a model"; "motherhood"; and, "we don't have a model". These comments reflected a concern about the lack of operational focus in the model. A fundamental conclusion of this evaluation is that the model development process was not completed and that the "model" which was turned over to the East Prince Health Region was not implementable.

Informants involved with the demonstration project who have operational experience in government identified concerns about the inherent difficulties in the use of a resource allocation model for this population. They noted a characteristic of existing practices is that government directly funds service providers and is thus able to insist on a minimum level of standards. While these informants agreed that clients themselves may be able to achieve a higher and more responsive level of service, they continue to see advantages from government ensuring standards are at an acceptable level. They are unsure how they can perform this role without a contractual role with service providers. In particular, concern was expressed about the possible accountability of government for injury or abuse of an individual.

Related to this point is the inherent difficulty which reduced use of existing facilities and agencies presents. Government has traditionally provided funding for agencies to run certain programs for persons with intellectual disabilities. The model envisions a future where individuals will have control of the funding and can purchase services from existing agencies as well as other sources. Clearly, the expectation is that existing agencies would:

- receive a declining share of resources expended on the population; and

- in response to consumer demand, offer more inclusive services focussed on individual needs.

In the short term such a transition must either reduce the funding provided to agencies or increase the total expenditures for services to the population. Since the latter is unlikely, it is inevitable that agencies — as well as individuals and families who are dependent on their services — will regard such reform as hostile and resist it.

In conclusion, our evidence indicates the Choice and Opportunity Model was not a model but instead a vision. In effect, it painted a

picture of a better approach but it failed to describe how to get there. Our informants were in general agreement with this vision but quite critical of the amount of time it took to get there.

Issue 1 b) Are the community development plans suitable for the target group?

The Choice and Opportunity Project has made substantial investments in identifying the needs of the client population. None of our informants expressed the view that additional efforts in identifying needs would be worthwhile. On the other hand, some individuals were of the view that this work delayed, and thus limited, community development initiatives. The research into the needs of persons with intellectual disabilities and their families was considered to be of high quality, but opinions were mixed as to how much this work added to the pre-existing state of knowledge. Informants from the Government of Prince Edward Island indicated that a "made in Prince Edward Island model" was viewed as essential to achieving "buy-in". However, lack of "buy-in" continues to be an issue primarily because of other significant changes (Health Reform, change of many senior officials shortly after project initiation and more recently, election of a new government with a different agenda as regards community development). In retrospect, many informants were of the view that the extensive research conducted in the early stages of the project diverted both time and resources which might have been used more effectively. Criticism of this nature was especially strong from families of individuals with a disability.

Issue 2 Is the resource allocation model consistent with the province's health reform?

Prince Edward Island's Health Reform Strategy is targeted at changing the focus of health care delivery from illness to health. The Strategy identifies six strategic areas as follows:

- health promotion and illness prevention;
- community care and support;
- public participation in health planning;
- individual, family and community responsibility for healthy lifestyle choices;
- appropriate access and utilisation of services; and
- services based on need which demonstrate potential benefits.

Informants universally agreed that the resource allocation model was highly consistent with this strategy. However, several informants noted the province's commitment to health reform became quite uncertain after a change in government. Others noted that implementation of the Choice and Opportunity Project during the early stages of health reform was a limiting factor. In particular, the challenges which health reform presented to government made it very difficult to get the Choice and Opportunity Project "on the agenda" of senior officials. As one informant noted (and several others agreed), "we had more important problems than Choice and Opportunity."

3.2 Design and Delivery — Model Development

Issue 3 Have operational, legislative, regulatory or jurisdictional constraints been identified and addressed in the model development process?

Informants identified several operational constraints that had not been adequately identified and addressed in the model development process:

- the model was not accompanied by an operational plan which would have provided guidance to demonstration staff as to how to go about trying to implement the model;
- although significant discussion was held on the impact on existing service providers of the substantial changes inherent in the model, this issue was not resolved prior to model demonstration. As a consequence, the model demonstration focussed on individuals who either did not access pre-existing services or accessed them in a limited way;
- despite the significant involvement of all partners in model development over an extended period of time, the commitment and support of the Government of Prince Edward Island was unclear at the end of model development[c]. As a result, the demonstration commenced with very limited guidance to demonstration staff as to what approaches would be acceptable to Regional Health Officials; and
- the traditional role of government in dealing directly with service providers was not addressed. Since this has been the major role of government in the past, complete abandonment of this function was not considered realistic. During model demonstration, traditional arrangements have been maintained with pre-existing suppliers but significant confusion exists regarding government's role in monitoring the activities of new suppliers which clients may wish to utilise.

The model was developed through consultation among the partners and, in particular, through the efforts of the Model Development Working Group. The working group included representation of researchers with expertise relating to disability issues, parents of persons with intellectual disabilities, and existing service providers.

Clearly, it would have been unrealistic to expect such a group to provide clear operational guidance. Several informants noted the Smith-Green study[7] was intended to provide an operational plan to implement the approaches described in the model.

However, the Smith-Green study did not deliver an operational plan. Instead it offered sweeping recommendations to make fundamental changes to the Choice and Opportunity Project. These recommendations included changes to the roles of various partners and to the management of the project. Some of these recommendations were implemented. At that stage, however, an operational plan still did not exist and the project was rapidly running out of time and needed to proceed with the demonstration.

An important lesson learned relates to the need for a more comprehensive transition strategy when instituting radical change. In particular, such a strategy would need to address:

- what needs to be retained from what existed before the development of the new approach;
- what needs to be dismantled, how is this to be achieved and what is an appropriate timetable;
- how to continue to provide services to individuals with disabilities during the transition period;
- identification of the individuals/organisations who will need to cooperate for the new approaches to be developed and successful;
- acquire the support of the identified individuals/organisations; and
- to the extent that required support is not obtained, make adjustments to the new approaches.

Since the project lacked a comprehensive transition strategy, it moved to its demonstration phase with the following disadvantages:

- very limited operational guidance as to how to implement the new approaches proposed by the model;

- confusion about responsibility of government to monitor the services provided by new suppliers identified by clients;
- significant ambiguity as to what would be acceptable to senior officials of the East Prince Regional Health Authority°; and
- unclear accountabilities.

Issue 4 Is the resource allocation model consistent with the principles outlined in the framework document?

Yes, the resource allocation model developed is consistent with the principles in the framework document. The principles outlined in the framework document were that the project "will help to achieve the inclusion of persons with intellectual disabilities in their communities and promote lives to be characterised by:

- personal control and autonomy;
- individualisation and self-determination;
- inclusiveness and accessibility;
- non-intrusiveness;
- flexibility and community involvement;
- sustainability; and
- safety and security.

While the model is certainly consistent with these principles, the lack of an implementation plan — and more specifically a transition strategy — created a risk that the model demonstration might diverge from both the framework and the model.

Issue 5 Were the roles and responsibilities of the various partners clear for model development and implementation?

No. The role of partners was a complicated issue for this project.

HRDC's role was clear and realistic. They were the funder of the project and they were expected to provide advice and guidance through their involvement on the various study groups.

The roles of the CACL and PEIACL are somewhat more confusing. Both organisations are distinct from government. Indeed, a major

purpose of both organisations is to advocate for the needs of the populations they represent. Clearly, this role frequently involves them in confrontation with government. At the time of the initiation of the Choice and Opportunity Project, both organisations had experienced cutbacks in funding from government.

To a large extent, the mechanisms employed in the project have prohibited the two ACL's from acting as partners. Both have received stable funding over the four years from the project and are major beneficiaries of the project. It is difficult — if not impossible — for a significant beneficiary to be a partner. In the Choice and Opportunity Project, both ACL's are beneficiaries, partners and agents of the project. Clearly, each has the capacity to act effectively in all three roles. However, the combination of the three roles is troubling. This is perhaps best seen by examining the role which developed for the Government of Prince Edward Island.

The Government of Prince Edward Island is the fourth partner in the project. They had the responsibility to administer the project; to co-ordinate the various initiatives; and to implement the model demonstration. This was an all-encompassing role, which was severely constrained by the roles of the other partners. First of all, 31% of the budget was allocated to the two ACL's and most of this funding was untied; i.e., was not dependent on achievement of specific deliverables. Both of these organisations were able to provide valuable skills and support for the project. Our interviews confirmed that many valuable contributions were indeed made. However, because the project supported them through blanket funding and the organisations were equal partners, no client-agent relationship existed. This limited the Government of Prince Edward Island in its initiatives to co-ordinate efforts towards meeting project objectives. Nor was there a clear allocation of responsibilities as would be expected in a co-operative approach among equal partners pursuing the same agenda.

The community development initiatives present a good example. PEIACL has a significant responsibility for delivery of this set of initiatives in all regions of the province. As an arms-length organisation, it is working in this area in a way which is consistent with its own values, resources and expertise. In a true partnership, the four partners would have decided more precisely their objectives and plans for initiatives in this area and purchased services to meet these objectives. This might well have lead to different agents (and objectives) in different regions. Each would have been tied to clear deliverables. But since PEIACL is both a partner and the primary agent, a risk exists that insufficient resources are available to utilise other agents which might have relevant skills and expertise for some aspects of the community development agenda.

Strengthening of PEIACL was a legitimate and necessary initiative of

the project if objectives were to be achieved. However, this could have been achieved with a lower level of blanket funding. This would have left more resources under the control of the partnership to pursue specific community development initiatives. PEIACL would not have been precluded from also acting as an agent for these initiatives and might well have received equivalent levels of funding under an alternate approach if they were the best available supplier. However, the funding related to delivery of community development initiatives would then have been provided under quite different terms and conditions. This would have ensured the partnership as a whole directed the community development component of the project.

Issue 6 Is the model being implemented as planned?

No. Initial expectations were for model development to advance to a further state (i.e., complete with implementation details) in substantially less time. This would have allowed a demonstration of the new approaches across the province and provided ample time for learning in a variety of environments.

Instead, the demonstration project proceeded on a limited scale in only one of the five health regions. The limited time available (complicated by the need to spend time developing implementation approaches) clearly limited the potential for learning. However, implementation in one region (especially a region which only had one service provider) further limited the potential for learning.

The Operations Committee perceived advantages from implementing the model in a region where the traditional services available to the client population were provided by a single supplier. This was an accurate judgement in the context which existed. Without a detailed transition strategy, multiple service providers would have been a significant complication, especially in view of the limited time available for demonstration. Further, the single supplier in East Prince had indicated a willingness to make adjustments consistent with the model. Nevertheless, successful demonstration in such a region would still have left many unanswered questions about the viability of the new approaches in areas where multiple suppliers exist, not all of whom might be expected to be co-operative.

It is our assessment that the adjustment to the project of moving from a province-wide demonstration to a demonstration in East Prince severely limited the extent of learning which could be expected to occur.

More seriously, the lack of a clear plan as to how to implement the model resulted in a much less comprehensive demonstration experiment than had been anticipated. In effect, the failure to complete

the model development resulted in a project demonstration which consisted of minor adjustments within the existing systems and processes as opposed to the radical restructuring which had been identified in the Framework Document.

Issue 7 What are the particular strengths and weaknesses of the model?

The major strength of the model is that it focuses on meeting needs rather than providing services. All our informants supported this direction. The major weakness of the model is that it provides such limited guidance as to how to actually implement this alternative approach.

Issue 8 What were the expenditures for model development?

Based on data provided by project staff, we have estimated expenditures for model development at approximately $1.05 million. This breaks down roughly to $240,000 in funding for CACL and contracts with the Roeher Institute; an estimated $60,000 of the total funding provided to PEIACL; an estimated $420,000 of the expenditures of the project relating to staff, administration and equipment; and approximately $328,000 for consultant studies.

Issue 9 What lessons can be learned from model development on effective interventions for the intellectually disabled?

Two important lessons have been learned from model development.

The first lesson relates to the need for comprehensive planning and accountability in order to accomplish reform of government social service systems. Government social service systems serve disadvantaged individuals. Consequently, it is critical that reform initiatives incorporate comprehensive planning and accountability to ensure clients will not be at risk during the transition. This did not occur in the Choice and Opportunity Project and, inevitably, the scope of the reform was reduced.

The second lesson relates to the importance of defining roles and responsibilities in a partnership. It is difficult to conceive of a more challenging partnership than that created for the Choice and Opportunity Project. Partnering between the federal government, a provincial government, a national and a provincial advocacy group was bound to be difficult. Doing so on a project whose scope was so comprehensive but somewhat unclear increased the inherent difficulty. The failure to define clear roles and responsibilities — including accountabilities — for each of the partners thus became a limiting factor.

4.0 Evaluation Findings — Community Development

One of the underlying assumptions of the Choice and Opportunity Project is that there are resources within communities to respond to the needs of persons with intellectual disabilities. The thrust of the community development component is building the capacity of communities (key leaders, community service clubs, businesses, churches, recreational groups, municipal councils, education systems, etc.) to integrate persons with intellectual disabilities as meaningful citizens.

As reflected in the Community Development Strategy Proposal (June 25, 1996) the essential task was to prepare the broader community environment for the successful implementation of the Choice and Opportunity Implementation Model. In order to accomplish this task, the following objectives were articulated:

- develop a community development strategy consistent with the guiding principles of the Choice and Opportunity Project, and which identifies and animates the untapped capacity of both the mentally-disabled citizens and their families, the resources within the system, and the community at large;

- develop a community development team whose purpose would be to provide leadership and modelling for the capacity-building approach with individuals and families, the health regions, and communities generally; and

- provide ongoing training and support for community resource workers to assist them in carrying out their leadership/support roles in their respective regions and communities.

Consistent with the importance of community development:

- an estimated 60% of project funding related to community development;

- of 45 issues identified by the Evaluation Committee, 20 relate to community development; and

- addressing the community development issues has required an extensive array of methodological approaches. In addition to the use of evidence from key informant interviews and document reviews, the findings provided here also rely on:

- workshops and follow-up interviews with individuals involved in community development from all five health regions;
- community case studies relating to the Queens and West Prince regions.

4.1 Relevance — Community Development

Issue 1 Are the community development processes suitable for increasing community inclusion for the target group?

Community development processes can make a significant contribution to increasing community inclusion for the target group by focusing on building the capacities of individuals, families and communities which will address the ongoing (sustainability) needs of persons with disabilities. From the beginning, the Choice and Opportunity Project saw community development as the single most important component to the success of the project. Key informants in all sectors of the project talked extensively about the suitability of community development processes and structures that facilitate inclusion of the target group.

A wide range of processes are significant to increasing community inclusion for the target group. While no one process by itself can address the issue, the combination of these initiatives can significantly contribute to the inclusion of persons with disabilities into community life.

Based on interviews, focus groups and a review of project documents, community development in the Choice and Opportunity Project has included:

- making contacts with businesses to educate them on the Choice and Opportunity Project and the potential contribution of persons with disabilities;
- involving parents in planning for service delivery strategies;
- finding creative supports for persons to help themselves and articulate their needs;
- working with NGOs in finding new ways to move persons into the community;
- helping families, particularly older parents of persons with disabilities, to deal with their fear of change in service delivery strategies;

- promoting community partnerships with business, families and government workers;
- talking to a full range of community resource persons about the Choice and Opportunity Project;
- working with staff in group homes to include parents in the planning process;
- identifying key people in the community to make it work;
- involving community resource workers as part of community committee structures;
- understanding that any community development initiative needs to be guided by issues related to sustainability;
- recognising that the system needs to support the role of the family support worker as a legitimate partner in the community development process; and
- understanding that community development strategies are driven by family/individual needs.

Both in the community case studies and in the focus groups relating to community development, we identified several examples of how individuals, organisations and businesses have reached out and included persons with intellectual disabilities. In Queen's County, progress seems to have been greatest, and ACL representatives noted several instances where they have been approached by individuals and organisations wishing to include persons with intellectual disabilities.

Only in the demonstration region (East Prince) has our methodology included systematic examination of changes in the lives of individuals through 14 case studies. Of the 10 adults (or older adolescents), at least four have experienced greater interaction with the community through the course of the project. In one case, the individual's mother noted a much improved attitude at the school he attended and attributed this to workshops, etc., conducted as part of the Choice and Opportunity Project. Outside of school, little change had occurred for this family and the mother was quite critical of the project. For three other individuals, greater inclusion has resulted. This greater inclusion has typically resulted from efforts of the family support worker and/or as a consequence of new services received through the Choice and Opportunity Project funding.

Issue 2 a) Is the resource allocation model relevant to meeting the needs of the intellectually disabled within Prince Edward Island?

One of the underlying principles of the model is to develop community resources that fit the identified needs of individuals, rather than having individuals fit into existing services. This is a fundamental shift from existing methods of service delivery which do not address individual needs and, more significantly, tend to isolate persons with intellectual disabilities from their communities.

As reflected in the Choice and Opportunity Model, the aim of the resource allocation model is to achieve inclusion of persons with intellectual disabilities in their communities and promote lives characterised by: personal control and autonomy, individualisation and self-determination, inclusiveness and accessibility, non-intrusiveness, flexibility and community involvement, sustainability, safety and security. These elements of the resource allocation model are consistent with meeting the needs of the intellectually disabled within the province.

Issue 2 b) Is it consistent with provincial priorities?

The philosophy and underlying principles of the Choice and Opportunity Project are consistent with government priorities. In particular, the community development process being used by the project reflects initiatives to build community capacity to facilitate inclusion of persons with disabilities.

While there has been a change in government since the introduction of the Choice and Opportunity Project, it was noted that this government is also committed to the philosophy and principles of the project, e.g., community-based care, individual responsibility for health. It was suggested that the Choice and Opportunity Project was a "mini-version" of Health Care Reform. This involves a public and private shift in thinking about health care delivery, focusing on strategies such as: health promotion and illness prevention; community care and support; public participation in health planning; individual, family and community responsibility for healthy lifestyle choices; appropriate access and utilisation of services; and services based on need which demonstrate potential benefits. One key informant suggested that "community development is the cornerstone of Health Reform in P.E.I."

Issue 3 Are the needs identified prior to Choice and Opportunity Project still present?

The community development component of the project is at the early stages of addressing the needs identified prior to the project. There is still considerable work to do and the degree of work varies from region to region.

Community development is a process of building networks, partnerships and relationships. Therefore, the process of "inclusion" and "community capacity building" is slow. While there are a considerable number of successes in terms of addressing individual needs, key informants suggested that building the capacity of communities to integrate persons with disabilities requires considerably more time and planning.

Assessing the extent to which community development has succeeded is difficult. Our evidence consists of:

- evidence from key informants indicating positive responses from individuals/organisations who are asked to include a person with an intellectual disability;
- evidence — at least in Queen's County — that some organisations/individuals are starting to take a proactive approach to inclusion;
- several examples of individuals whose lives include greater inclusion than in the past; but
- the reality that most adult members of the population remain largely isolated — either at home or in segregated programs.

This continuing degree of isolation is not — in our judgement — evidence that community development has failed. Instead, it is attributable to a variety of other factors:

- **Health and other barriers of participants.** Several of the individuals in our case studies have not become more involved in their communities because of poor health or other disabilities. These difficulties are not insurmountable but greater inclusion of these individuals will require more than acceptance of inclusion by the community.
- **Lack of change by service providers.** Most adult members of the population continue to be served by pre-existing service providers. The evaluation has not included a comprehensive review of all service providers. However, our evidence indicates that change in the practice of service providers has been minimal and that their services, for the most part, are provided in isolated environments.

- **Failure to implement a resource allocation model.** The Choice and Opportunity Project has not led to any significant change in the mechanisms through which support is provided to individuals. In the demonstration region, some individuals received access to incremental supports during the demonstration. However, no significant progress was achieved in reallocating funding from service providers to individuals.

Continuing benefits can be expected to be achieved from further community development efforts. For these benefits to be sustainable, it is necessary to find ways to assist individuals to take advantage of their more inclusive communities by reallocating funding from agencies to individuals.

Issue 4 What evidence indicates that government priority areas are being addressed by the Choice and Opportunity Project?

The background documents outlining government health reform priorities identify the following two principles reflected in the Choice and Opportunity Project. They are:

- that improvement in health status can be achieved by the general community, service providers and government working in partnerships to identify and respond to health needs of Islanders;

- the structure of the health system must reflect the community-based approach that puts decision-making at the lowest level possible, fostering a style of open communication and a sense of "working together".

While the five Regional Health Boards have been able to incorporate flexibility, decision-making, planning and delivery of health and social services closer to the community level, implementation of consistent policies among regions lacks a fully developed central provincial monitoring structure.

Partnerships at the community level between project staff, government workers and relevant community groups are gradually being identified and created, often based on individual needs. As suggested in the initial needs assessment, the community is for the most part open to the idea of inclusion but is not clear on strategies and initiatives for implementation. This is where partnerships with community resource workers (PEIACL) and family support workers (Government of Prince Edward Island) are all important for meeting the objectives of the project. (Partnerships in relation to the management of the project will be addressed in Issue 10.)

4.2 Design and Delivery — Community Development

Issue 5 How and to what extent has the project assisted in identifying and addressing jurisdictional issues?

It is our understanding that there has been no review of the legislation or policies that may facilitate or create barriers to the implementation of the Choice and Opportunity Project. This has created some difficulty in interpreting policies at the operational level when it comes to the reallocation of government funds to persons with disabilities.

Issue 6 Have any weaknesses of the Choice and Opportunity Project organisational structure identified in the Phase I evaluation been corrected?

Issues identified in the Phase I evaluation focused on internal and external communications and the partnerships, both at the community and the project management levels. The issue of partnerships is specifically addressed in Issue 10 of this report.

The presence of a full-time director for the project has facilitated the flow of communications. Since PEIACL has taken over the community development process, communication between Community Resource Workers and the project is improving.

Issue 7 Was the funding provided sufficient to meet the project objectives?

Yes. There was no indication that there was not enough funding to meet the objectives of the project. This was verified by all key informants.

Issue 8 Did the model account for current resources?

There are two distinct types of current resources:

- **Dedicated resources.** These represent the resources that are currently expended to provide services to persons with intellectual disabilities. These resources typically include funding provided to service providers for day programs and alternative living arrangements as well as funding provided to individuals for income support, transportation, respite care, etc.

- **Generic resources.** These resources, available in the community, may provide services for various persons with intellectual disabilities.

In neither case could it be said that the model accounted for current resources. In the demonstration region, dedicated resources were examined by the demonstration staff and alternatives considered. However, even in the demonstration region, no detailed accounting of the dedicated resources was prepared for consideration of the partners.

Similarly, with the generic resources, individual community resource workers (employed by PEIACL) and family support workers (employed by the Province) certainly identified resources and pursued the possible use of these resources for individuals. However, the project did not result in a comprehensive identification of the resources that could be drawn upon.

Issue 9 Could baseline information be developed for the total provincial population?

Baseline data was collected for the project during the formative evaluation in March 1996. This information was very general. It had been anticipated that the project would produce a profile of the client population across the province. Such a profile was expected to include, at a community level, the number of persons with intellectual disabilities and their distribution according to the following characteristics:

- age;
- nature of disability;
- assistance/services required; and
- current use of services/resources.

Such a profile was never prepared. A partial exception applies to the demonstration region where most individual members of the client population were identified. For these approximately 150 individuals, their age, the nature of their disability, and, in most cases, their current use of services and resources were identified. However, the nature of services required was identified for about only 50 of these individuals. This information was not analysed in an aggregate form.

Issue 10 Are the roles and responsibilities of the various partners clearly enunciated and carried out for community development and for project implementation?

Through the evolution of the project, PEIACL was primarily responsible for community development. PEIACL was a logical

organisation to implement the community development component, as policy development and program implementation would not be consistent with government's role. However, as noted in Issue 5 of Chapter 3, the specific mechanism for funding PEIACL's involvement has limited its accountability to the other partners. In practice this has meant that PEIACL — rather than the partnership as a whole — has been responsible for community development. This has limited the achievements under community development.

First of all, it has limited the contributions from CACL and HRDC. CACL and HRDC, with their national mandates, have knowledge of community development experiences in other jurisdictions and with other client groups. As well, both organisations have resources of potential value. Clearly, PEIACL consulted and made use of this knowledge and these resources. Nevertheless, a greater involvement by CACL and HRDC in the design and monitoring of the community development process would have been valuable.

The limited role of the Government of Prince Edward Island in community development was a more serious limitation. The provincial government had two important roles to play:

- assisting in the definition of the scope of community development efforts. Its particular contribution would have been in identifying priorities based on where the formal system could best take advantage of community resources;

- with greater involvement in defining and prioritising needs, the province would have had a greater responsibility to use community resources and to work in concert at an operational level with PEIACL and others. The overriding responsibility of PEIACL for community development had the unintended effect of limiting the province's accountability for making greater use of community resources.

The partnerships at the operational levels have thus had different levels of success. For the most part, the community resource workers and the family support workers share the project's philosophy and principles. The partnerships become unclear in regions that have not identified a formal mechanism that allows partners to work together on specific objectives and implementation plans. Some key informants expressed confusion about the lack of clear roles and responsibilities and mechanisms that link the partners. Based on our focus groups, the working relationship among the various stakeholders appears stronger in some regions than others.

Issue 11 Were the project objectives of community development clearly outlined and understood in all regions?

The project objectives of community development were not clearly understood by all the key stakeholders in each region. The structure for monitoring consistency, in terms of the implementation of the project objectives in each region, has been at the advisory level (e.g., Provincial Demonstration Committee and Regional Advisory Committees). Because of the devolution of decision-making to the Regional Health Boards, this has created inconsistent understanding of the project objectives and uneven "buy-in" to the project across the province.

While it may not have been necessary to develop a detailed plan, there was consensus that the implementation of the model was delayed because there was a lack of overall planning and direction at the provincial level. As a result, it took some time for the regions to fully understand the implications of executing the broad objectives identified for community development. As has been mentioned, the regions, including those in the pilot project, have had to take a conceptual framework and develop their own operational strategy.

Issue 12 ***Do the province-wide community development activities have the potential to increase the inclusion of the client group?***

Yes. The community development activities have a great deal of potential to increase inclusion. Community development is a process that takes time and considerable "grass roots" work. Through the work of the community resource worker, community development is the major vehicle for capacity building and inclusion. There are a growing number of examples of how community resource workers are developing opportunities for inclusion at the "grass roots" level.

As reflected in the initial needs assessment research, overall, communities were open to the idea of inclusion, but they were unsure how to create activities and initiatives that could make this a reality. It was noted that this process would not only be developing specific activities to integrate persons with disabilities but would need a conscious effort to change people's attitudes, values and ways of thinking. The question was not only how the community could take more responsibility for contributing to the quality of life of persons with disabilities, but also, could the community see the contribution these persons make to the community (e.g., in the educational, employment, recreational and social spheres, etc.).

At this point, communities seem more open to developing policies that accommodate the objectives of the project (i.e., resource allocation, or funding) than is the formal system. While the system buys into the values and principles of the Choice and Opportunity Project, Regional

Health Boards and CEOs have difficulty implementing them. Front line workers will need further clarification and support to identify funding mechanisms that can facilitate the reallocation of resources. One informant posed the question, "Is the cost to the regions too high if existing funding policies are applied?" While this latter point is not a community development issue per se, it does have implications for the link between activities initiated by community resource workers and the resource reallocation issues (funding) related to the Choice and Opportunity Project.

It is our assessment that the potential achievements from community development are constrained by the relatively limited change which has occurred in the formal system (i.e., governments and service providers). Government needs to respond to individual needs, and service providers need to take advantage of community resources if community development is to achieve its potential and be sustainable.

Issue 13 Is the community development process on target in all regions to achieve the objectives established in the plan?

The community development process is not on target in all regions as originally planned. While there are a growing number of examples of individuals who have been integrated into community activities, at this point the objective of developing the long-term capacity of communities to include persons with disabilities has not been achieved.

Sustainability has been a critical component of this project and will only be achieved when the system and the communities are able to reallocate resources according to the principles outlined in the model. These partners must develop an understanding of the needs of persons with disabilities; begin to include them in activities in the community; and shift their thinking, attitudes and behaviours to an intuitive or feeling level, ensuring that persons with disabilities become part of the culture and mandate of community life. (See Issue 14 for further information on sustainability.)

At the same time, there are concerns about the delivery structure of the system. Because of the devolution of decision-making to the regions, there are inconsistencies across the province in terms of interpretation of policies and support for the project. It is difficult to influence and hold five autonomous Regional Health Boards accountable to a central structure. Regarding the Choice and Opportunity Project, it will be important to further develop policies that set provincial standards and to develop an accountability framework with performance measures.

There has also been a significant lack of planning at the provincial level, particularly in terms of the reallocation of funding resources

within the system. This is an issue that will have particular relevance to sustainability.

4.3 Success — Community Development

Issue 14 What community resources have been developed or enhanced in the various regions as a result of the project?

Community resource workers have facilitated partnerships at the community level, for the most part, based on individual need. There are many examples of how recreational, social or service organisations have created resources or reallocated resources in order to respond to persons with disabilities. Examples have included these: changing recreational policies at the municipal level in order to include persons with disabilities in summer recreation programs; public health nurses including persons with disabilities in their presentations on sexuality; developing partnerships with community stakeholders that focus on strategies for promoting persons with disabilities to be included in new employment opportunities (New Employment Opportunities Now — NEON); local 4-H associations including persons with disabilities in their summer programs; and health authorities hiring a co-ordinator to develop and implement an Early Intervention and Support Service focusing on children and young adults aged 0 to 21. Many examples have been documented in monthly Project Update and "Success Stories of Inclusion, Empowerment and Choice", September 1997.

The community resources are being developed and enhanced by leadership of the community resource workers who advocate in the communities, facilitate initiatives, and develop strategies for inclusion; the Choice and Opportunity Project funding to help carry out the community development process; and development of key community partners to facilitate inclusion. Sustainability will result when there is a shift in thinking and philosophy at the community level.

Achieving sustainability involves a range of methods and strategies, which together will contribute to this objective. Some of these include:

- provincial government committing to the principles of the project, not only at the philosophical level but also at the policy level in order to lever change;
- leadership at the provincial level so that standards and policy implementation are monitored and applied consistently and core programs are maintained within the system;
- the need to develop a transition plan for provincial implementation of the project;

- the continuation of the social marketing strategy on a provincial level for the duration of the project;
- key stakeholders at the community level maintaining existing partnerships and finding ways to create new ones on an ongoing basis, so that communities take ownership of inclusion;
- the need for a person to co-ordinate communication and information flow among partners at the provincial and regional levels;
- advocating for policy changes at the community level, e.g., in the area of transportation, access to recreational facilities, education, employment, etc.;
- a network of strong associations at the provincial and regional levels to monitor and lobby change that will enhance inclusion; and
- ensuring adequate information on resources and programs is available to families.

Issue 15 Are community groups throughout the province helping to enable participants to be successfully integrated into community life?

As reflected in Issue 14.

Issue 16 What were the expenditures by regions? What effects were obtained?

As described in Section 2.7, we have estimated that $3,112,000 was expended on Community Development throughout the course of the project. Allocation of these expenditures by region is not possible. As indicated in Section 2.7, $335,000 was provided to the five regional health authorities (in aggregate) in each of the last three fiscal years. The funding provided to PEIACL (approximately $1.2 million over the four years of the project) includes salaries for community resource workers operating across the province. Most other expenditures identified in Section 2.7 were not specifically targeted to individual regions.

Issue 17 How and to what extent has the project contributed to building networks among participants, governments, NGOs, employers and community groups?

At the operational level of the project, networks between the key

stakeholder groups are being built on a case-by-case basis. It was suggested that while these experiences are evolving, it will take further work to build permanent networks (sustainability) that are guided by the philosophy of inclusion.

It was noted both in key proponent interviews and the background documents that the community development process (building networks being part of this process) takes a long time. It is difficult for both the system and families to unlearn traditional ways of thinking and find new ways of doing business together. There is also a need for a commitment to a strong partnership between the family support worker and the community resource worker, involving the family in planning initiatives.

Issue 18 Has the project improved the quality of life throughout the province for persons with intellectual disabilities?

As noted above, there are an increasing number of individual cases and initiatives that have contributed to an improved quality of life for persons with intellectual disabilities. At this point, it would be premature to suggest that the long-term capacity of communities for inclusion exists throughout the province.

Issue 19 To what extent has the model aided the integration of individuals in the various regions into community life?

The Choice and Opportunity Model has provided a broad framework and sets out important principles that potentially contribute to inclusion. It is our assessment that not only has the project provided important funding for certain initiatives, there are some examples and even greater potential for the system and community to explore new ways of working together to improve the quality of life for persons with intellectual disabilities.

Issue 20 Is it feasible to integrate the model in the other regions of Prince Edward Island?

To this point, the feasibility of implementing the Choice and Opportunity Model has not been established in any of the regions. Community development efforts in all regions have been encouraging and — as previously noted — several examples where individuals have greater involvement with the community can be identified. However, obstacles remain:

- in all regions, the majority of the adult population continues to either:
    - rely largely on service providers who — for the most part — provide services in an environment which is segregated

from the community at large; or
- spend most of their time at home with little community interaction;

- the formal system continues to relate to these service providers in essentially the same fashion as always. A significant goal of the Choice and Opportunity Project was to place decision making relating to access to services in the hands of individuals and their families. However, for those individuals who have accessed services traditionally provided to the client population, their only decision is whether to keep using these services. If they elect not to access these traditional services, the options available to them are very limited and not materially different from the situation prior to the Choice and Opportunity Project.

While the community development initiatives have advanced the agenda and resulted in more inclusive attitudes **and practices** by individuals and organisations, most persons with intellectual disabilities are not fully integrated into their communities.

5.0 Evaluation Findings — Model Demonstration

One of the goals of the Choice and Opportunity Project was to demonstrate the resource allocation model and to learn lessons that would assist in possible future implementation of the model in other jurisdictions. The East Prince Health Region was selected for the model demonstration. The demonstration commenced in December 1996 and continued until March 1998. The East Prince Health Region is a largely rural area of the province that includes the community of Summerside. Most adults in East Prince receive services from Community Connections, which consists of two vocational centres and a residential agency:

- **Industrial Park Location.** There are approximately 50 individuals who attend a day program at this facility on the outskirts of Summerside. Most of these individuals spend the majority of their time in attendance working on-site.

- **Spring Street Location.** This facility accommodates 12 full-time individuals who are considered to have higher needs than the clients at the industrial park location. The facility is primarily regarded as providing respite care for the families of its clients.

- **Residential Services.** Residential services consists of a group home with five or six full-time residents as well as an alternative

living program which involves 30 to 40 clients.

As noted in Chapter 3, Issue 1(a), "A fundamental conclusion of this evaluation is that the model development process was not completed and that the 'model' which was turned over to the East Prince Health Region was not implementable." Clearly this conclusion affects the responses to the 16 issues identified for model demonstration.

The methodologies applied to addressing these 16 issues include:

- key informant interviews;
- a document review; and
- 13 case studies[a] relating to individuals in East Prince. The case studies examined the circumstances of these individuals at three points in time — prior to the demonstration (February 1997); during the demonstration (October 1997); and after the demonstration (June 1998).

5.1 Relevance — Model Demonstration

Issue 1 ***Within the demonstration region, to what extent does the model reach the intended target group?***

For the majority of individuals with intellectual disabilities in the demonstration region, the Choice and Opportunity demonstration made little difference. There are two primary exceptions:

- **Pre-schoolers.** The Choice and Opportunity project implemented an early intervention project for pre-school children with autism-like symptoms. A consultant was hired to work with seven families in East Prince and the project also funded the participation of the families in a recognised intervention program (CARD), on a proposal put forth by a local paediatrician. This early-intervention approach is consistent with the literature and can be expected to greatly enhance the potential for these individuals to be productive members of their communities.
- **Individuals who were clearly dissatisfied with pre-existing services.** The demonstration staff concentrated their efforts on individuals and families who were clearly dissatisfied and had complained about the services they received. Many of these either were not using conventional services (i.e., Community Connections) at all or were using them on a limited basis. Several of them were individuals who had specific well-defined needs, which could not be met within the funding system that

existed prior to the project (e.g., speech therapy, and access to greater amounts of respite care than allowed under the province's guidelines).

This focus on specific populations was a significant diversion from the intent of the model to implement a new and more inclusive approach to providing services for all members of the population. It was also quite logical, however, given that — as previously noted — the demonstration staff had received no guidance as to how to apply the model with individuals who were significant consumers of the services provided by Community Connections.

Issue 2 Are the services provided at both the individual and community level consistent with the needs of the target group?

This question can best be addressed based on the age of individuals:

- the services provided to pre-schoolers during the demonstration were highly consistent with the needs of these individuals. Four of our case studies (four families, one of which had two disabled pre-schoolers) involved pre-schoolers. In all four cases, we encountered truly desperate situations in our pre-demonstration visit. The families were on the verge of collapse and held out little hope for the future of their children. In our subsequent visits to all four families the progress was remarkable, as described in the case study report:

  > *"Prior to Choice and Opportunity, the families had been isolated in their situations with few external supports. All were struggling to cope, with such considerations as placing the child out of home, marital stress and separation, financial concerns and feelings of guilt, grief, failure and hopelessness. Since the interventions of C and O have been implemented, they report a greater sense of comfort and control in their parenting of their children, acceptance of the long-term realities involved, and a clear understanding of the supports they require to function effectively.";*

- individuals of school age are primarily served by the education system and have not been examined in the evaluation;

- individuals nearing school completion have a more difficult "school-to-work" or "school to?" transition than most students. Community Connections operates a school-to-work transition program of limited duration. During the demonstration, this population was given some attention and, for example, some

were referred for an assessment for supported employment. However, this was conducted on an experimental basis. As the case study report states, the dilemma for persons who have recently left high school or will in the next few years is this:

> *"While Community Connections remains full and is not able to take in new people, there are no emerging alternatives. There are signs that this is resulting in inactivity amongst young adults with an intellectual disability. The families involved are finding increased levels of stress with less supports. This has some potential to result in family placement breakdown, as well as increasing reliance on Community Connections, as opposed to development of an array of service options.";*

- for older individuals, the lack of alternatives to Community Connections means there is a real threat posed by plans to change the status quo. Neither the model development phase nor the model demonstration made any real progress with developing a process for transferring some support from a sheltered workshop environment to more community-based approaches. Seven of our case studies related to adults who receive services from Community Connections. For these individuals, if Community Connections decreases its services, there will be at least an interim period when some individuals and their families will have no options for external services and supports. In several of the situations we examined, this would be a significant burden.

5.2 Design and Delivery — Model Demonstration

Issue 3 ***Is sufficient baseline information being collected for the demonstration region? Have adequate tracking systems been put in place to collect information on participants and interventions?***

The model demonstration has essentially involved attempts to facilitate with clients who received limited service and expenditures in the past and to assist them to identify and acquire services that may be beneficial. Given this approach, the issue is not relevant.

Issue 4 ***Are the roles and responsibilities of the various partners clearly enunciated and carried out in the demonstration region?***

The Government of Prince Edward Island had sole responsibility for the demonstration of the model in East Prince.

Issue 5 ***Is the model being implemented as planned in the demonstration region?***

No. There have been variations from the planned implementation of the model:

- initial plans were to have a single facilitator work with individuals and their families to identify services. This was revised at an early stage so that the individual engaged as a facilitator, trained other family support workers to serve the facilitator role;

- initial plans were to prepare a service grid that identified services for which clients were eligible and how the services could be accessed. The intent was to ensure that the system would be fair, with all clients having equal access to them. This was abandoned as unfeasible due to ambiguity about service eligibility;

- demonstration of the model was expected to involve re-examination of service delivery to all persons with intellectual disabilities. Instead, the focus has been on individuals who had specific unmet needs and had complained about the inadequacy of service and pre-schoolers;

- while the intent of the model — and the demonstration — was to reallocate pre-existing expenditures, there has been virtually no change to any pre-existing expenditures. The changes that can be attributed to the demonstration involve new expenditures that applied for the duration of the demonstration (e.g., CARD program for pre-schoolers including the employment of an early intervention worker; speech therapy; supported employment assessments).

Issue 6 ***a) What are the strengths and weaknesses of the model being implemented?***

b) Has the project identified that there are gaps in essential services?

c) How have these gaps been dealt with?

The strengths of the model compared with those of earlier approaches, which do not adequately meet the needs of the population and unnecessarily isolate persons with intellectual disabilities from their communities, are:

- a greater focus on the needs of the client population;

- self-selection of services to be accessed; and
- a greater use of natural supports available within the community.

The weakness of the model is that it provides little guidance as to how to make the difficult transition from funding of service providers to supporting individuals.

Gaps in existing services were not a major barrier for the project. For example, while there was not an established supported employment in East Prince, a provider for this service was identified in a neighbouring community, and a small number of individuals were referred. A similar approach was applied to speech therapy.

Issue 7 ***a) What resources have been allocated for the target group for disability-related supports?***

b) What resources have been spent on the project? Are the resources adequate to achieve desired ends?

c) To what extent are there additional resources for new or enhanced initiatives? Have existing resources been used to continue activities carried out prior to the pilot? Have resources been redirected to new or enhanced activities?

Section 2.7 provides the profile of expenditures on the project. The specific demonstration activity in East Prince — as previously noted — did not result in any significant reductions in planned expenditures. During the course of the demonstration, some additional expenditures occurred and were funded from the resources provided to East Prince Health by the Choice and Opportunity Project.

Issue 8 ***Were the objectives of community development clearly defined and understood?***

See Issue 11 in Section 4.2.

Issue 9 ***Do the community development activities in the demonstration region have the potential to increase the inclusion of the client group?***

Yes, the 14 case studies provide evidence of this. Of the 10 adults (or older adolescents) who were the subjects of the studies, at least four have experienced greater interaction with the community through the course of the project. In one case, the individual's mother noted a much improved attitude at the school he attended and attributed this to such activities as workshops that were conducted as part of the

Choice and Opportunity Project. Outside of school, little change had occurred for this family, and the mother was quite critical of the project. For three other individuals, greater inclusion has resulted.

The greater interaction of the other three individuals has typically resulted from efforts of the family support worker and/or as a consequence of new services received through the Choice and Opportunity Project funding.

5.3 Success — Model Demonstration

Issue 10 ***What community resources have been developed or enhanced in the demonstration region as a result of the project?***

East Prince — like the other regions of the province — has been affected by the various community development initiatives undertaken over the four years of the project. We have not attempted to identify all such developments in East Prince. Instead, we have answered this question in regard to community resources, which have been developed or enhanced as a result of the demonstration in East Prince. We are aware of four specific areas where community resources have been affected by the demonstration:

1) Services to Pre-schoolers

During the demonstration, Choice and Opportunity funded the involvement of an early intervention support worker relative to application of CARD, a recognised intervention program for autistic pre-schoolers in East Prince. This project was based on a proposal by a local paediatrician. Based on early successes, the support worker's term was extended twice. Since June 1998, when the Choice and Opportunity Project funding for the initiative ended, the paediatrician has been successful in acquiring a research grant which will make the services of a support worker trained in CARD available for two years. Our four case studies with pre-schoolers showed very positive results and substantial improvements in quality of life for both the pre-schoolers and their families. Consequently, the availability of this new service is a very positive development.

2) Supported Employment

Prior to the demonstration, no supported employment services were available in East Prince. In the course of the demonstration, a private service provider was used to help families identify one-on-one supports including supported employment. The cost for this service was $2,600. It is our understanding that there is no anticipation that services of this individual will be used on a regular basis.

3) Speech Therapy

During the demonstration a private provider of these services was identified and served a number of clients.

4) Community Connections

Community Connections has supported some of the concepts of the model, and East Prince Health and PEIACL tried to work with the service to revise its approaches. In general, these attempts have not been productive and have not resulted in any major adjustments in the practices of Community Connections.

Issue 11 How satisfied are participants with various aspects of the project, e.g., community support, application and selection, usefulness of services provided and competence of service delivery personnel?

From the case studies, it is clear that dissatisfaction with the Choice and Opportunity Project was very high among the families of persons with intellectual disabilities. The common perspective was that the Choice and Opportunity Project was an expensive program that has not resulted in sustaining services to persons with disabilities in East Prince. Family members noted that the project enhanced neither choices nor opportunities for adult persons with intellectual disabilities. There was a consistent message from families, some of whom have participated in numerous forums, programs and reviews over the past 30 years, that the need is for action, not deliberation and research.

A particular concern related to services for adults. Before, during and after the demonstration, Community Connections remains the one stable organisation offering services to this population. Families and individuals were not universally pleased with this service and were dismayed with the lack of alternatives. However, some were very concerned that (in their view) the Choice and Opportunity Project was attempting to destroy a service that they know and rely on without any viable alternatives.

A partial exception to the general view of dissatisfaction relates to the families of the pre-schoolers. These families were delighted with the intervention worker who assisted them and clearly identified substantial benefits that had been realised by their children as well as substantial strengthening of their families. They were very grateful that the Choice and Opportunity Project had made these benefits possible. However, there was also some resentment that they had lived with the threat of cancellation of this initiative, and they were dumbfounded by

the decision to withdraw the Choice and Opportunity Project funding in June 1998 in view of the enormous benefits which had been realised by their families.

Issue 12 What were the expenditures in the demonstration region? What effects were obtained?

In Section 2.7, it is indicated that a total of $420,000 of funding was provided to East Prince Health by the Choice and Opportunity Project. An estimated 25% of this relates to community development, leaving $315,000 that can be attributed to model demonstration. The benefits achieved were:

- significant benefits for seven pre-school children and strengthening of their families' abilities to provide the supports these individuals are likely to need in the future; and
- provision of small amounts of additional services for adults with disabilities (e.g., some respite care, some speech therapy, some supported employment and some medical equipment).

Issue 13 How and to what extent has the demonstration facilitated networks among participants, governments, NGOs, employers and community groups?

This evaluation has provided no evidence that the demonstration has facilitated such networks.

Issue 14 Has the demonstration improved the quality of life for persons with intellectual disabilities?

The demonstration has significantly benefited autistic pre-schoolers and their families. Other persons with intellectual disabilities have received minimal or no improvements to their quality of life as a result of the demonstration.

Issue 15 a) What lessons can be learned from the demonstration on the most effective interventions in assisting the intellectually disabled in dealing with barriers to their social and economic problems?

b) What lessons would be applicable to other segments of the population and other jurisdictions?

As noted under earlier issues, the demonstration has generally not resulted in effective interventions. The exception is with pre-school children. The literature establishes that the pre-school age is the ideal time to intervene with persons with intellectual disabilities. This

project has certainly underlined previous research that well-designed interventions with pre-schoolers cannot only have positive developmental impacts on the individuals but can also strengthen the family's ability to assist the person with the disability on an ongoing basis.

With adults, the lessons learned relate to how difficult it is to move from the isolated service approach, which has been in place for many years, to a more responsive and inclusive approach such as envisioned by the Choice and Opportunity Model. The realities of pre-existing approaches in East Prince (and many other parts of Canada) are as follows:

- the non-institutionalised population divides into two groups:
  - the first group participates in day programs run by agencies. The day programs may include training and work (typically in sheltered workshop environments), but their major value to disabled individuals — and their families — is typically the safe environment they provide (essentially respite care) and the social interaction. The programs are largely funded by government but also may rely on fundraising and revenue from the "workshop". The government funding is typically based on operating five days a week for up to a specified number of individuals;
  - the second group receives very little if anything in the way of services or government funding related to their disability. Some members of this second group contribute to their families and communities but many lead mostly unproductive and idle lives at home. Often, members of this group have some prior experience with day programs but have opted not to continue to attend. However, young adults have frequently not had this prior experience for two reasons. First, these individuals are comfortable with more inclusive approaches due to their experiences in the education system and may not be interested in the day programs. Secondly, in many communities, existing day programs have long waiting lists;

- most of the government funding (other than social assistance payments) relates to the first group. However, more inclusive approaches for this group will not necessarily reduce the costs of running the day program and would likely lead to new expenses relating to this group. For example, reducing an individual's attendance from five days a week to two or three days a week will not necessarily reduce the costs of running the day program and may well necessitate additional expenditures to support the individual on the days when they no longer attend the day program. Such new expenditures for individuals who

already consume significant amounts of government funding cannot easily be justified;

- conversely, since the second group consumes few services at present, application of the Choice and Opportunity Model would inevitably lead to incremental expenditures for these individuals. Such expenditures would likely be cost-effective in the longer term (reducing the risks of family placement breakdown) and would be equitable (given the relatively high expenditures for members of the first group) but are problematic in the short term in an era of declining or stable government budgets. The Choice and Opportunity demonstration — conducted in a very brief time period and with clear directives to avoid non-sustainable expenditures — was limited to small funding allocations to deal with issues where a short-term benefit was possible (e.g., speech therapy);

- government and advocacy groups are increasingly uncomfortable with the day programs as presently constituted. Disabled individuals and their families (or caregivers) typically do not regard the programs as ideal but are dependent on them.

Changes to this reality are incredibly difficult. Most of the resources are in the hands of the agencies running the day programs, and many members of the population utilise virtually no resources, while others (i.e., those attending the day programs) utilise significant resources. Reforming the system by reallocating existing expenses would inevitably produce winners and losers:

- agencies would need to be funded in a different way and probably at a lower level. Clearly the agencies and their current customers will resist;

- providing services to individuals who currently receive little can only be accomplished with new money or by reducing services to individuals who currently receive more.

It is hardly surprising that the East Prince demonstration failed to make any substantial progress in demonstrating the effectiveness of the Choice and Opportunity Model.

Issue 16 ***a) Is the model a cost-effective way of delivering services to the intellectually disabled or are there more efficient methods of achieving the same objectives?***

b) What investment would be required to make it work elsewhere?

Since the demonstration has not been able to produce evidence that

the model can work, questions of cost-effectiveness cannot be addressed — cost-effectiveness is only relevant once effectiveness is established.

Our conclusion — given the contextual realities identified under Issue 15 above — is that significant reform and progress towards the Choice and Opportunity Model will occur in one of three ways:

- slowly, as agencies respond to the different demands they will face from younger families who expect a more inclusive life for disabled individuals in their families;

- by eliminating or radically altering the current funding of agencies, which would inevitably cause significant hardship for the current clients of these agencies at least in the short term;

- by providing new options to disabled individuals and their families while leaving existing options in place.

This last option would inevitably necessitate incremental expenditures at least for the short term. The reason that many families on Prince Edward Island were so dissatisfied with the Choice and Opportunity Project is that they had thought that the project was an experiment with this third approach. They were very frustrated that significant amounts of money were spent on research, consultation and consultants, while very little — if any — was available to assist disabled members of their families.

A second important point regarding cost-effectiveness relates to the cost of family placement breakdown. In our case studies, family members noted that if they do not receive the supports they require to function, placement outside the family may be necessary. Most families are inclined to resist this option as long as possible based on their perception of what is best for their family member. However, they are often frustrated that government appears to fail to recognise that family placement is not only usually in the best interest of the individual — and the family — but is also much less costly for government. These individuals argue that a more flexible approach, which is designed to provide families with the supports they require to function, will be more cost-effective in the longer term.

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Footnotes

1 See Prince Edward Island Choice & Opportunity - Social Marketing Plan, Centre for Social Marketing, Carleton University, October 16, 1996. ▲

2 See "Marketing & Communications Plan - Choice and Opportunity Model". ▲

3 In particular, the model developed is an allocation model rather than a service model. It is not intended to simply create new services for the client group but to liberate the resources currently assigned to the population so that they could be used in a more flexible and client-centred fashion. ▲

4 Amounts have been rounded to the nearest $5,000 and where expenditures vary between years, average amounts have been provided. ▲

5 Actual expenditures vary from year to year. The four-year subtotals, however, are consistent with actual expenditures for the project. ▲

6 A subsequent change of government further complicated this matter. ▲

7 Smith Green and Associates Inc. is a management consulting firm with significant experience as regards the Health and Social Services systems in Prince Edward Island. ▲

8 This ambiguity proved to be an even more important factor with the election of a new government early in the demonstration phase. ▲

9 Originally, 17 individuals were selected for case studies. One declined to participate, one moved from the region and two others could not be contacted for the third phase of the case study. It had been originally intended to select the case studies at random from the approximately 150 persons with intellectual disabilities in East Prince. However, when selecting the cases in February 1997, it became apparent that many of the 150 individuals would likely be unaffected by the demonstration (see Issue 1). Consequently, 11 of the case studies were selected from the approximately 50 individuals who had been identified as candidates for alternative services. ▲

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